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$^p$ preliminary
$^r$ revised
x suppressed to meet the confidentiality requirements of the *Statistics Act*
$^E$ use with caution
F too unreliable to be published
* significantly different from reference category ($p < 0.05$)

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# Child functional characteristics explain child and family outcomes better than diagnosis: Population-based study of children with autism or other neurodevelopmental disorders/disabilities

*by Anton Miller, Jane Shen and Louise C. Mâsse*

## Abstract

**Background:** Allocation of resources for services and supports for children with neurodevelopmental disorders/disabilities (NDD/D) is often based on the presence of specific health conditions. This study investigated the relative roles of a child's diagnosed health condition and neurodevelopmental and related functional characteristics in explaining child and family health and well-being.

**Data and methods:** The data on children with NDD/D (ages 5 to 14; weighted n = 120,700) are from the 2006 Participation and Activity Limitation Survey (PALS), a population-based Canadian survey of parents of children with functional limitations/disabilities. Direct and indirect effects of child diagnosis status—autism spectrum disorder (ASD)/not ASD—and functional characteristics (particularly, ASD-related impairments in speech, cognition, and emotion and behaviour) on child participation and family health and well-being were investigated in a series of structural equation models, while controlling for covariates.

**Results:** All models adequately fitted the data. Child ASD diagnosis was significantly associated with child participation and family health and well-being. When ASD-related child functional characteristics were added to the model, all direct effects from child diagnosis on child and family outcomes disappeared; the effect of child diagnosis on child and family outcomes was fully mediated via ASD-related child functional characteristics.

**Interpretation:** Children's neurodevelopmental functional characteristics are integral to understanding the child and family health-related impact of neurodevelopmental disorders such as ASD. These findings have implications for the relative weighting given to functional versus diagnosis-specific factors in considering needs for services and supports.

**Key words:** Child development disorders, child health services, disabled children, family health, health services needs and demand, resource allocation

Children with neurodevelopmental disorders/disabilities (NDD/D) or "neurodisability"[1] are the largest identifiable subpopulation of children with disabilities[2] and account for 7% to 14 % of all children in developed countries.[3,4] NDD/D comprise an array of conditions characterized by impairment in posture-mobility, cognitive-adaptive functioning, communication, relating socially, and regulating emotions and behaviour; biological or physical markers of a specific medical condition may or may not be present. Diagnoses under NDD/D include autism spectrum disorders (ASD), intellectual or learning disabilities, attention-deficit/hyperactivity disorder (ADHD), cerebral palsy, and Down and fetal alcohol syndromes.

Children with neurodisability require services and supports that span the health, educational, and family and social services sectors.[5] Health conditions, as listed in diagnostic taxonomies such as the International Classification of Diseases (ICD)[6] or the Diagnostic and Statistical Manual of Mental Disorders (DSM),[7] often predominate in eligibility criteria for services and supports,[8-10] or form the basis of "disability categories" on which the provision of educational supports is determined.[11-14] However, this approach has been challenged by calls to emphasize individuals' functional characteristics[9,15-18] rather than the diagnosis category in which they are placed. These concerns arise in light of advances in the conceptualization of disability, along with recognition of the limitations of categorical diagnostic classification systems in mental and developmental health.[19,20]

The World Health Organization's 2001 International Classification of Functioning, Disability and Health (ICF)[21] has advanced the conceptualization of disability in three ways:

- Disability is framed as the converse of healthy functioning.
- Functioning/Disability, health conditions (diagnosed diseases and disorders), and contextual factors (environmental and personal) are distinct components of the framework.
- Disability results from interactions between health conditions and contextual factors.

In the ICF, functioning is understood to manifest at the level of body, person, or person-in-society, operationalized respectively as intactness (or impairment) of body structures or physiological functioning, ability (or limitation) to carry out daily activities, and participation (or restriction) in meaningful activities with other people. While the ICF framework and concepts are increasingly being adopted and deployed in clinical and research contexts,[22,23] empirical research into the dynamics and mechanisms of interactions among diagnosed health conditions and functional characteristics remains limited.

The appropriateness of using categorical diagnosis classifications in mental and developmental health has been questioned because of concern about the validity of conditions so defined[19]; the clinical heterogeneity of persons grouped under one diagnosis category such as ASD[24]; and the functional and diagnostic complexity of children with NDD/D.[2,25] Clinicians observe considerable overlap in the day-to-day functional characteris-

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tics of children diagnosed with different NDD/D, despite the distinctness of symptom sets for conditions such as ASD, ADHD, or intellectual disability.

Empirical evidence of the roles of diagnosis versus functional characteristics in child and family outcomes could inform policy on services and supports for children with neurodisability. To this end, a national disability dataset, the 2006 Participation and Activity Limitation Survey, was used to study relationships between a child's diagnosis status (ASD versus other neurodevelopmental diagnoses), a range of functional characteristics that were largely neurodevelopmental or psychological, and measures of child and family health and well-being. The analysis examined whether the functional characteristics most closely associated with a diagnosis of ASD (communication, learning, and regulation of emotions and behaviour) mediate associations between a child's diagnosis status and the physical and psychological health of parents, the economic well-being of the family, and the child's participation in various activities, while controlling for other functional characteristics less closely associated with ASD (hearing, vision, mobility, dexterity and pain) and for demographic variables. It was hypothesized that neurodevelopmental and related functional characteristics would be more informative than a child's diagnosis in explaining child and family outcomes, and would largely or fully mediate apparent effects of diagnosis. ASD was selected as the "reference diagnosis" because of increases in its prevalence and the impact on public health and services.[26,27] Also, funding programs have been implemented specifically for children with ASD, although an ASD diagnosis is recognized as being one among many factors relevant to understanding the characteristics and needs of affected children and their families.[28,29]

## Data and methods

### Data source

The 2006 Participation and Activity Limitation Survey (PALS) is a national post-censal survey of adults and children who had a disability (operationalized as experiencing limitation in everyday activities due to a health condition/problem). PALS participants were selected from the 2006 Census of Canada based on responses to two general "filter" questions about activity limitations, as well as age and geography. For those younger than 15, the Child Questionnaire was used to determine the nature, severity, and impact of disabilities (vision, hearing, communication, mobility, dexterity, learning, developmental and emotional or psychological conditions), and to identify conditions and diagnoses that limit participation. Telephone interviews were conducted during 2006/2007 with 7,072 parents/guardians ("parents") from a sample of approximately 9,000. The data were weighted following adjustment for patterns of non-response and various child characteristics,[30] yielding a weighted sample of 340,340.

**Table 1**
**Characteristics of children aged 5 to 14 with neurodevelopment disorders/disabilities and their families, household population, Canada, 2006 (weighted n = 120,700 unless otherwise stated)**

| Characteristic | Mean | Standard deviation | % distribution |
|---|---|---|---|
| **Age (years)** | 10.01 | 2.71 | ... |
| **Sex** | | | |
| Boys | ... | ... | 67.1 |
| Girls | ... | ... | 32.9 |
| **Residential location** | | | |
| Urban | ... | ... | 80.5 |
| Rural | ... | ... | 19.5 |
| **Family income (n = 120,570)** | 70,700 | 55,700 | ... |
| **Diagnosis status** | | | |
| Autism spectrum disorder (ASD) | ... | ... | 17.2 |
| Other neurodevelopment disorders/disabilities | ... | ... | 82.8 |
| **ASD-related functioning (range: 0 to 3 for HUI and PALS; 0 = maximum impairment, 3 = no impairment)** | | | |
| 3 HUI[a] attributes related to speech, emotion and cognition (n = 112,490) | 2.47 | 0.42 | ... |
| 3 PALS[b] impairment indices related to speech, emotion and cognition | 1.80 | 0.82 | ... |
| **Other functioning (range: 0 to 5 for HUI and 0 to 4 for PALS; 0 = maximum impairment, highest score = no impairment)** | | | |
| 5 HUI[a] attributes related to vision, hearing, mobility, dexterity, and pain (n = 110,260) | 4.74 | 0.45 | ... |
| 4 PALS[b] impairment indices related to vision, hearing, mobility, and dexterity | 3.60 | 0.60 | ... |
| **Family outcomes (range: 0 to 1; 0 = worst, 1 = best)** | | | |
| Physical health[c] (n = 97,140) | 0.66 | 0.23 | ... |
| Psychological well-being[d] (n = 96,110) | 0.64 | 0.19 | ... |
| Economic impacts[e] (n = 97,170) | 0.76 | 0.25 | ... |
| **Child outcomes (range: 0 to 1; 0 = least, 1 = most)** | | | |
| In-school participation[f] (n = 115,970) | 0.60 | 0.36 | ... |
| Out-of-school participation[g] (n = 115,890) | 0.45 | 0.17 | ... |

... not applicable

[a] Health Utilities Index (HUI) measures degree of ability versus impairment (for example, ability to be understood when speaking)

[b] Participation and Activity Limitation Survey (PALS) measures presence and severity of impairment (for example, difficulty making oneself understood when speaking)

[c] One question about parents' usual state of health compared with others

[d] Four questions: satisfaction with life (excellent to poor), amount of stress (not at all to extremely), not enough time for oneself (rarely to always), and stress about childcare and other responsibilities (never to always)

[e] Eight yes/no questions about parents' career and finance (for example, child's condition led to quitting work, changing work hours, financial problems)

[f] Four yes/no questions about participation in physical education or organized physical activity, playing with others during recess or lunch hour, school outings, and classroom participation

[g] Six questions about leisure and social activities participation in the community (for example, sports with coach, non-sports activities such as music and summer camp) with response options everyday to never, except summer camp (yes/no)

**Source:** 2006 Participation and Activity Limitation Survey.

The current study pertains to children aged 5 to 14 who were attending school because data on participation in various activities were available for them. The analyses were limited to children with NDD/D as identified through a method described in previous work with PALS, who accounted for almost three-quarters of 5- to-14-year-olds with disabilities in the dataset.[2] This involved classifying children into one of six NDD/D groups that reflect the most widely acknowledged functionally based domains of child development (motor, speech-language, learning/cognition, social, sensory, and psychological). Classification followed a detailed review of all ICD-10 codes available for each child, with consensus between two developmental pediatricians, triangulation of unclear cases with a third reviewer, and elimination of cases deemed unclassifiable.[2]

The current study was approved by the University of British Columbia's Research Ethics Board.

## Measures

*Child's diagnosis status:* ASD diagnosis (yes/no) was ascertained from the presence of relevant ICD-10 codes (F84.0-F84.5, F84.8 and F84.9) based on information provided by parents during the PALS interview. This included their perception of their child's main/most responsible health conditions, or their response to a question about a number of specific chronic conditions, one of which was professionally diagnosed autism.

*Child's functional status comprised:* 1) functional domains most closely associated with a diagnosis of ASD; and 2) other domains. The three most relevant domains for ASD-related functioning available in PALS were speech-communication, learning-cognition, and emotional-behavioural-psychological. The other domains were vision, hearing, mobility, dexterity, and pain. Two sources were used for child functional characteristics: items from the Health Utilities Index (HUI), slightly modified in PALS for the targeted age group,[30] and the PALS impairment index (Table 1). Two latent variables that captured the construct of a child's neurodevelopmental and related functional characteristics were created: 1) *ASD-related functional characteristics* ("ASD-related functioning"); and 2) *non-specific child functional characteristics* ("other functioning"). ASD-related functioning consisted of the three HUI attributes and the three PALS impairment index items most strongly associated with the core ASD impairments identified above. It was entered as a mediator in the analyses; other functioning (described below) was used as a covariate.

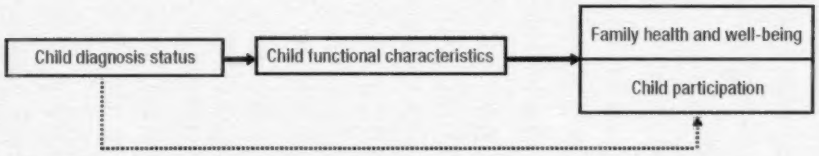
In accordance with the concept of family quality of life in the context of disability,[31] *family health and well-being* comprised physical health, psychological well-being, and the economic impact of having a child with a disability, as they relate to parents (Table 1). A second-order factor structure with psychological well-being and economic impacts treated as latent constructs and physical health as an indicator variable was supported by a Confirmatory Factor Analysis (CFA) performed in this sample ($\chi^2$(df = 64) = 418.56, $p < 0.001$; RMSEA = 0.048, 90% CI 0.044–0.052, p = 0.768; CFI = 0.933; and WRMR = 2.002; Appendix Figure A). Cronbach's alphas were 0.79 and 0.74 for psychological well-being and economic impacts, respectively.

*Child participation comprised in-school participation and out-of-school participation* (Table 1). A CFA performed in this sample supported the factor structure of child participation ($\chi^2$(df = 34) = 63.25, p = 0.0017; RMSEA = 0.018, 90% CI 0.011–0.025, p = 1.000; CFI = 0.958; and WRMR = 0.998; Appendix Figure B). Cronbach's alphas were 0.71 and 0.49 for in-school and out-of-school participation, respectively. The Cronbach's alpha was not optimal for out-of-school participation, likely because of lack of variance in the data for this construct.

The *covariates* entered into the analytic models were child age and sex, annual family income, residential location (urban/rural), and child "other functioning," which regrouped the remaining five HUI attributes and four PALS impairment items (Table 1).

**Figure 1**
**Schematic representation of direct and indirect effects models relating child diagnosis status and child functional characteristics to family health/well-being and child participation, household population aged 5 to 14, Canada, 2006**

**Direct effects model:** Child diagnosis has significant direct effect on family health/well-being and child participation.




**Indirect effects model:** Direct effect of child diagnosis status is no longer significant or no longer has meaningful effect when child functional characteristics are added, but an indirect effect is mediated via child functional characteristics.

**Source:** 2006 Participation and Activity Limitation Survey.

## Analyses

Using Structural Equation Modeling (SEM), three models were run. The covariates model examined the relationship among all covariates, and the three outcome variables—family health and

well-being, child in-school participation, and child out-of-school participation. The direct effects model tested whether a child's diagnosis status had a direct effect on the three outcome variables when accounting for the covariates. The indirect effects model tested whether a child's diagnosis status had an indirect effect on the three outcome variables with ASD-related functioning included in the model, and if so, whether the indirect effects were mediated by ASD-related functioning when accounting for the covariates (Figure 1).

Using MPlus software (version 7.11, MUTHÉN & MUTHÉN, Los Angeles, CA), the mean and variance-adjusted weighted least-squares method (WLSMV) was employed. Based on published criteria,[32,33] fit was considered to be acceptable if: Root Mean Square Error of Approximation (RMSEA) with an upper 90% confidence interval (CI) was < 0.08 or a p-value ≥ 0.05; comparative fit index (CFI) was > 0.95; and Weighted Root Mean Square Residual (WRMR) was < 1.0. Because of the strong influence of sample size on the statistical significance of correlation coefficients, a standardized path coefficient (SPC) was considered to have a direct or indirect effect on the outcomes only if it was statistically significant ($p < 0.05$) and had an absolute magnitude greater than .22 (thereby explaining at least 5% of total variance, approximately[34]). To compare models, the incremental r-square (percentage of additional variance explained by adding variables in a model) was examined, and an additional 5% of variance explained was considered to be meaningful. Finally, the Sobel test was used to test the significance of the mediated effects.[35]

## Results

Characteristics of the children and their families are presented in Table 1. Summary indices for the three SEM analyses are presented in Table 2.

All models adequately fitted the data—the RMSEAs were within acceptable ranges, although the CFI and WRMR were outside ideal range (Table 2). In all cases, examination of the modification indices did not uncover ways to improve model fit. Deleting non-significant paths can increase model fit, but in view of the confirmatory nature of these analyses, non-significant paths were not deleted.

The covariates model explained 11.6% of the variance for family health and well-being, 16.6% of the variance for in-school participation, and 16.4% of the variance for out-of-school participation.

In the direct effects model, child ASD diagnosis status had a significant and meaningful direct effect on family health and well-being (SPC = .29, $p < 0.05$) and on in-school participation (SPC = .35, $p < 0.05$) (Figure 2), but not on out-of-school participation (SPC = .10, p = 0.02), as the path coefficient did not meet the criterion for a meaningful magnitude of effect. Inclusion of child diagnosis status in the covariate model explained an additional 8% and 10.9% of the total variance in family health and well-being and in-school participation, respectively.

In the indirect effects model, the direct effects of child diagnosis status on child and family outcomes disappeared when ASD-related functioning was added (Figure 3), with SPCs no longer reaching thresholds for statistical significance or effect size magnitude. ASD-related functioning had a significant and meaningful direct effect on family health and well-being (SPC = .73, $p < 0.05$), in-school participation (SPC = .54, $p < 0.05$), and out-of-school participation (SPC = .25, $p < 0.05$). As anticipated, ASD-related functioning was also significantly related to child diagnosis status (SPC = .39, $p < 0.05$), meaning that absence of an ASD diagnosis was related to less impairment in the domains of speech and communication, cognition-learning, and emotional-behavioural/psychological functioning (Figure 3). Importantly, ASD-related functioning was a significant mediator between diagnosis status and family health and well-being ($z = 7.88$, $p < 0.05$), child in-school participation ($z = 7.18$, $p < 0.05$), and child out-of-school participation ($z = 3.38$, $p < 0.05$). Including ASD-related functioning in the model explained an

**Table 2**
**Structural Equation Modelling (SEM) relating selected characteristics to family health/well-being and child participation, children aged 5 to 14 with neurodevelopment disorders/disabilities, Canada, 2006**

| | | | Root Mean Square Error of Approximation | | | | | | Explained variance ($R^2$) | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | 90% confidence interval | | | | | | | Child participation | |
| Model | $\chi^2$(df) | p value[a] | from | | to | p value[b] | Comparative Fit Index[c] | Weighted Root Mean Square Residual[d] | Family health and well-being | In-school | Out-of-school |
| Covariates | $\chi^2$(df = 356) = 863.77 | p < 0.001 | 0.023 | 0.021 | 0.025 | p = 1.000 | 0.930 | 1.455 | 0.116 | 0.166 | 0.164 |
| Direct effects | $\chi^2$(df = 378) = 874.97 | p < 0.001 | 0.022 | 0.020 | 0.024 | p = 1.000 | 0.926 | 1.438 | 0.196 | 0.275 | 0.170 |
| Indirect effects | $\chi^2$(df = 429) = 1027.25 | p < 0.001 | 0.023 | 0.021 | 0.025 | p = 1.000 | 0.919 | 1.488 | 0.632 | 0.515 | 0.222 |

[a] p-value > 0.15 indicates good fit, but highly affected by sample size and complexity
[b] upper 90% confidence interval < 0.08 or p-value > 0.05 suggest adequate fit; primary value used to assess model fit
[c] value > 0.95 considered acceptable fit, but sensitive to non-significant paths
[d] value < 1.0 considered acceptable fit, but sensitive to non-significant paths

**Notes:** Covariates model includes child age and sex, family income, residential location, and other (non-ASD related) functioning. Direct effects model adds child autism spectrum disorder (ASD) diagnosis status to covariates model. Indirect effects model adds child's ASD-related functioning to direct effects model to test whether child ASD diagnosis status had indirect effect on child and family health outcomes via ASD-related functioning.
**Source:** 2006 Participation and Activity Limitation Survey.

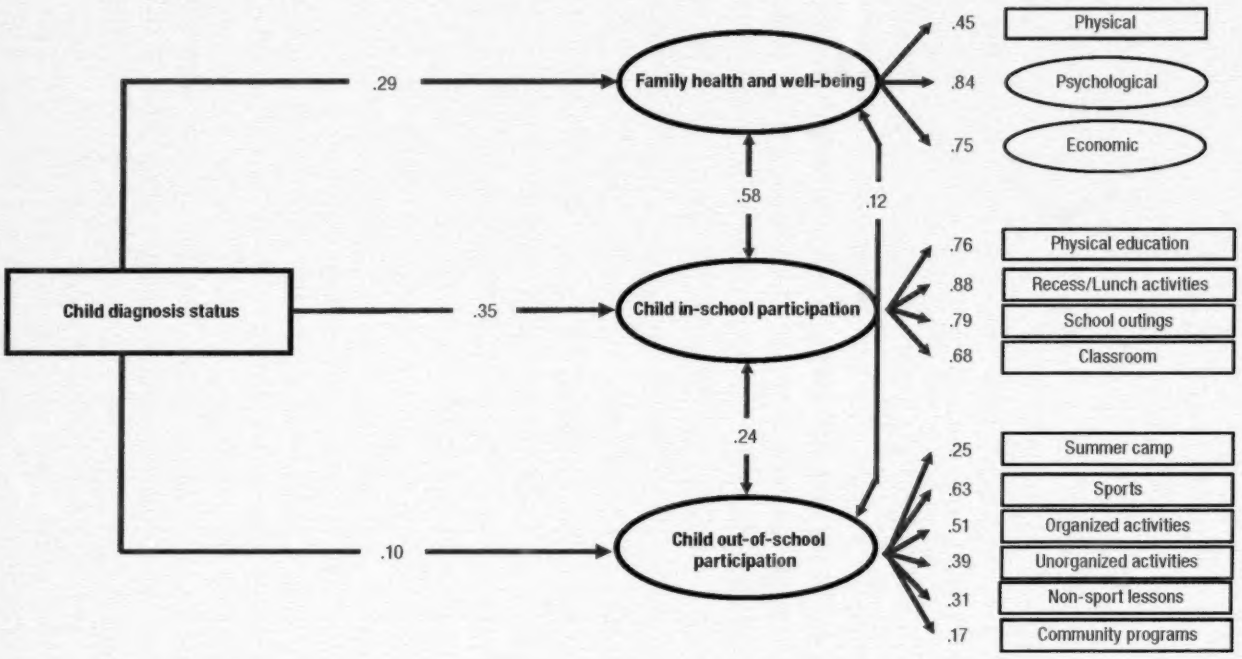
additional 43.6%, 24.0%, and 5.2% of the total variance in family health and well-being, in-school participation, and out-of-school participation, respectively (Table 2).

## Discussion

Consistent with the hypotheses, for children diagnosed with ASD or other NDD/D, neurodevelopmental functional characteristics more fully explained variance in family and child outcomes than did the child's diagnosis, and mediated the apparent effects of diagnosis status on these outcomes. To clinicians, these results may seem intuitive; however, the present findings contribute to evidence that may be relevant to thinking about and planning services and supports for children with neurodisability.[36,37] They highlight the importance of functional characteristics at a time when a given diagnosis often continues to be an important and sometimes major criterion in determining eligibility.

Previous studies demonstrated links between specific neurodevelopmental diagnoses and child and family outcomes,[38-40] but paid little attention to the possible explanatory role of the child's functional characteristics. One study found parental stress to be higher in families in which a child had been diagnosed with fetal alcohol spectrum disorder than with ASD,[38] but did not investigate variations in child functional or behavioural characteristics. Other studies reported an ASD diagnosis to be associated with higher unmet health care needs and more adverse family impact than is found in families of children with special health care needs in general,[39] or in families in which children had other developmental disabilities (Down syndrome, cerebral palsy or developmental delay) or mental health conditions (anxiety or behavioural problems).[40] Although the latter study took children's functional status into account, this was ascertained through a single generic question.[40] The composite measures in the present analysis were likely more sensitive because they involved ratings of functioning across an array of domains, and revealed that child functional characteristics better explained, and mediated, the apparent

**Figure 2**
**Direct effects model relating child diagnosis status to family health/well-being and child participation, household population aged 5 to 14 with neurodevelopmental disorders/disabilities, Canada, 2006**



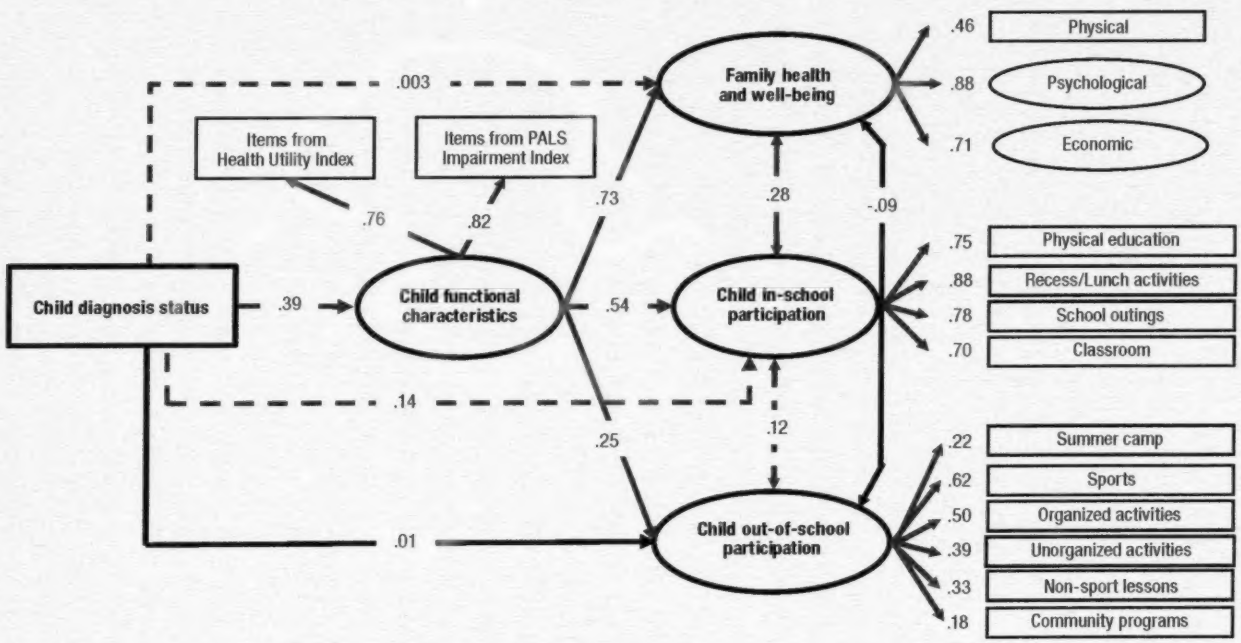

$\chi^2$(df = 378) = 874.97, p < 0.001; RMSEA = 0.022, 90% CI 0.020–0.024, p = 1.000; CFI = 0.926; WRMR = 1.438
df = degrees of freedom
RMSEA = Root Mean Square Error of Approximation
CI = confidence interval
CFI = Comparative Fit Index
WRMR = Weighted Root Mean Square Residual
**Note:** Model includes: child age, sex and other functioning; family income; and residential location.
**Source:** 2006 Participation and Activity Limitation Survey.

effect of diagnosis status. Kogan et al.[39] found that various emotional, developmental and behavioural problems, apart from an ASD diagnosis, predicted family impact and unmet needs, and that the child's functional ability was the strongest and most robust predictor. Despite these findings, the authors emphasized the role of a diagnosis of ASD in their conclusions.[39]

A limited body of work has explicitly examined the relative impact of diagnosis status and functional characteristics on caregiver health and service needs. According to Blacher and McIntyre,[29] a diagnosis of autism among young adults with cognitive-adaptive disabilities predicted poorer maternal well-being than did undifferentiated intellectual disability, cerebral palsy or Down syndrome. However, in additional analyses, they found the relationship to be almost entirely accounted for by the level of behaviour problems in the child. Other researchers reported that the need for home care supports among families in which a child had intellectual disability or other special needs was most strongly predicted by the child's degree of impairment in activities of daily living and intellectual disability, not by a diagnosis of intellectual disability *per se*.[10,15] Finally, among children with a wide range of chronic conditions and functional difficulties, measures of health services use, personal limitations, and family impact were all predicted by health conditions and by functional difficulties; however, functional difficulties were the stronger predictors for all outcomes except school absences.[16]

The present study confirms the importance of functional characteristics versus diagnosis status in explaining variations in family impact and child participation.[10,21,41] Demonstration of these relationships in a well-defined population of Canadian children with NDD/D strengthens the relevance of this work to the organization of health, rehabilitative and social services for children with neurodisability. These findings complement evidence of functional, diagnostic, and biological complexity among children with NDD/D,[2,25,42-45] and of the frequency of co-existing behavioural, emotional or other mental health

**Figure 3**
**Indirect effects model relating child diagnosis status and child functional characteristics to family health/well-being and child participation, household population aged 5 to 14 with neurodevelopmental disorders/disabilities, Canada, 2006**




$\chi^2$(df = 429) = 1027.25, p < 0.001; RMSEA = 0.023, 90% CI 0.021–0.025, p = 1.000; CFI = 0.919; WRMR = 1.488
df = degrees of freedom
RMSEA = Root Mean Square Error of Approximation
CI = confidence interval
CFI = Comparative Fit Index
WRMR = Weighted Root Mean Square Residual
**Notes:** Model includes: child age, sex and other functioning; family income; and residential location.
Dotted lines indicate path coefficients that became non-significant in Indirect effects model.
**Source:** 2006 Participation and Activity Limitation Survey.

issues,[46-48] which collectively reinforce concerns about the use of DSM or ICD categorical classifications for planning services. This study also illustrates the scope for innovative research on the dynamic inter-relationships among ICF domains.

### *What is already known on this subject?*

- Policies regulating access to services and supports for persons with disabilities are often based on diagnosis categories.
- Pediatric studies tend to focus on the impact of particular conditions, such as autism spectrum disorder (ASD).
- Expert opinion and a growing body of research attest to the importance of individual functional characteristics in understanding the impact of a disabling condition on a person's life, and thus, on the need for services and supports.
- Few studies have compared the roles of a given diagnosis versus functional characteristics in child and family outcomes.

### *What does this study add?*

- The functional characteristics of children with ASD or other neurodevelopmental disabilities are more informative in understanding a number of child and family outcomes, than is their being diagnosed with ASD.
- Child functional characteristics were found to mediate relationships between diagnosis and outcomes.
- The results suggest a need to emphasize functional characteristics over diagnosis categories in disability-related health and social policy.

## Limitations

The strengths and significance of these findings should be considered in the context of several limitations. The main variables were ascertained from parents' reports without corroboration of a child's diagnosis or functional characteristics by third parties. However, most survey-based research is subject to the same potential limitation. Also, the risk of misunderstanding and bias is reduced in PALS through collection of information by trained, experienced interviewers.

The cross-sectional design of this study reduces the ability to infer that outcomes were the result of differences in children's diagnoses or functional characteristics. In setting up the model, child ASD-related functioning was considered to be a proximal explanatory variable associated with aspects of child and family outcomes that possibly mediates relationships between diagnosis and "outcomes." The assumption was that individually measured characteristics tell more about how a child "is" in daily life (with consequences for participation and caregiving), than does knowing the child's diagnosis category. This assumption is supported by evidence of clinical heterogeneity and functional complexity within diagnosis categories.[2,24,25] In mitigation of this possible limitation, when the models were run with child diagnosis status as mediator, the results and conclusions were unchanged (data not shown).

It might have been preferable to have more fine-grained and investigator-selected items to analyze children's functional characteristics. Nonetheless, PALS provided consistent and uniform data with which to study diagnosis-functioning relationships among children with neurodisability.

Finally, the filter question used as part of the PALS post-censal strategy may have led to under-representation of people with mental and psychological disability.[49] The possible impact of this on child participants, and on the analyses, is unclear.

## Conclusion

These findings are most relevant to planning and providing services and supports for children with neurodisability. They are also relevant to clinicians who may focus mainly or exclusively on establishing a diagnosis. An expanded assessment horizon that includes measurement and documentation of individual functional characteristics would enable physicians to partner more fully with providers of ancillary and enabling services.[50] Future research might examine predictive interrelationships among diagnosis status, functional characteristics and outcomes for other neurodevelopmental and chronic childhood conditions, and how diagnosis status and child functional characteristics inter-relate in predicting family- and professional-perceived need for services and supports. ■

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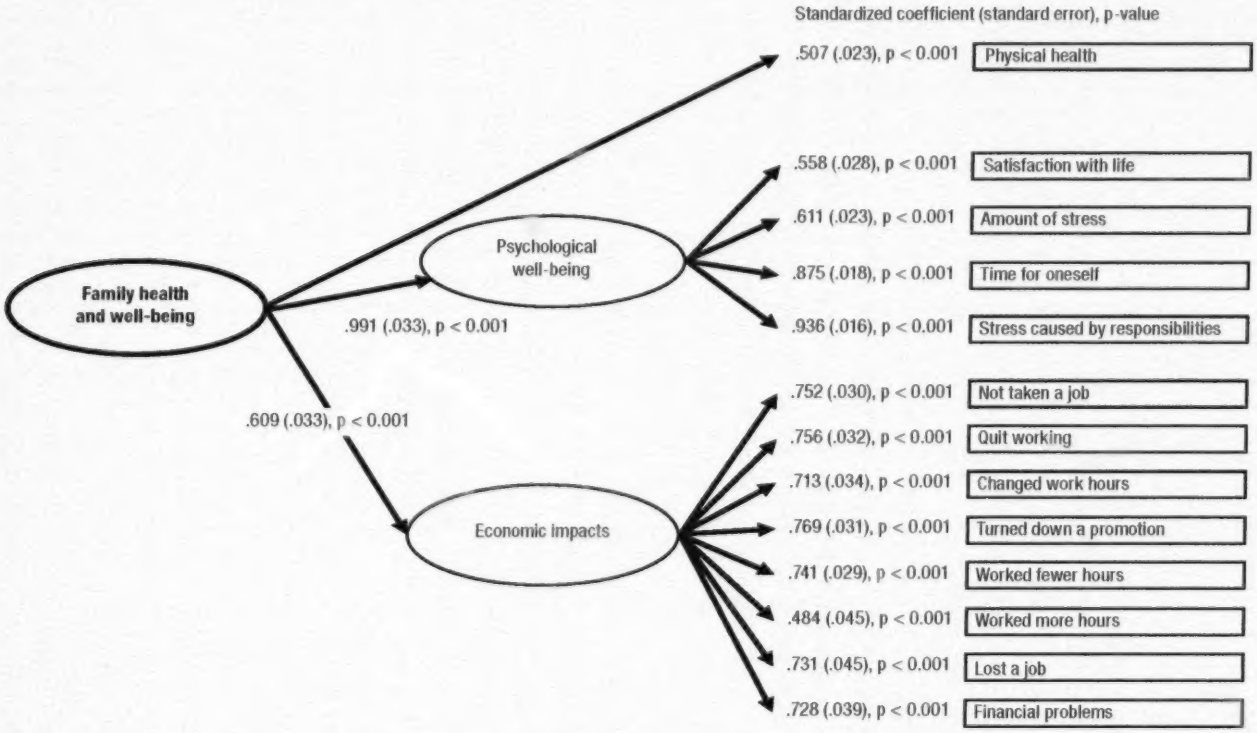
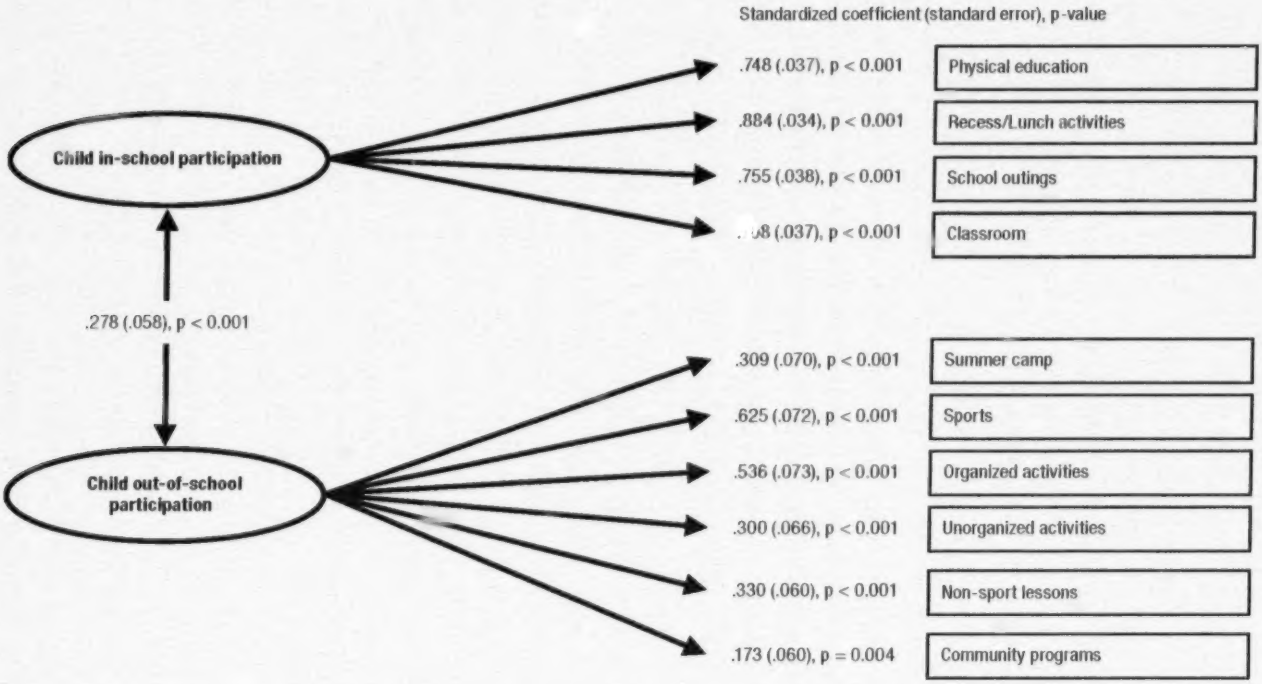
## Appendix

**Figure A**
**Psychometric properties of family health/well-being construct**


Standardized coefficient (standard error), p-value
Family health and well-being
Psychological well-being
Economic impacts
.991 (.033), p < 0.001
.609 (.033), p < 0.001
.507 (.023), p < 0.001
Physical health
.558 (.028), p < 0.001
Satisfaction with life
.611 (.023), p < 0.001
Amount of stress
.875 (.018), p < 0.001
Time for oneself
.936 (.016), p < 0.001
Stress caused by responsibilities
.752 (.030), p < 0.001
Not taken a job
.756 (.032), p < 0.001
Quit working
.713 (.034), p < 0.001
Changed work hours
.769 (.031), p < 0.001
Turned down a promotion
.741 (.029), p < 0.001
Worked fewer hours
.484 (.045), p < 0.001
Worked more hours
.731 (.045), p < 0.001
Lost a job
.728 (.039), p < 0.001
Financial problems

$\chi^2$(df= 64) = 418.56, p < 0.001; RMSEA = 0.048, 90% CI 0.044-0.052, p = 0.768; CFI = 0.933; WRMR = 2.002
df = degrees of freedom
RMSEA = Root Mean Square Error of Approximation
CI = confidence interval
CFI = Comparative Fit Index
WRMR = Weighted Root Mean Square Residual
**Source:** 2006 Participation and Activity Limitation Survey.

**Figure B**
**Psychometric properties of child participation constructs**




$\chi^2$(df = 34) = 63.25, p = 0.0017; RMSEA = 0.018, 90% CI 0.011–0.025, p = 1.000; CFI = 0.958; WRMR = 0.998
df = degrees of freedom
RMSEA = Root Mean Square Error of Approximation
CI = confidence interval
CFI = Comparative Fit Index
WRMR = Weighted Root Mean Square Residual
**Source:** 2006 Participation and Activity Limitation Survey.